# Routine antenatal HIV testing and informed consent: an unworkable marriage?[i]

**R Bennett**

This paper considers the ethics of routine antenatal HIV testing and the role of informed consent within such a policy in order to decide how we should proceed in this area—a decision that ultimately rests on the relative importance we give to public health goals on the one hand and respect for individual autonomy on the other.

A recent illuminating qualitative study by Zulueta and Boulton[1] explores the practicalities of informed consent in routine antenatal HIV testing. Its results support what I have argued[1] is inevitable with routine testing policies of this kind: that routine antenatal testing regimes are incompatible with requirements for informed consent. It has become clear that intervention could reduce the risk of transmitting HIV from mother to child from 15–20%[2] to around 8%,[3] or possibly as low as 2%.[4 5] The evidence of this possibility produced a general trend towards introducing routine antenatal HIV screening in developed countries worldwide.[6–10] The aim was to dramatically reduce the rate of HIV transmission from mother to child by encouraging universal antenatal HIV testing. The UK has been no exception, and in 1999 the government instructed health authorities to implement a policy of offering and recommending an HIV test to all pregnant women.[11]

This UK antenatal screening policy and others like it, although well-meaning, are problematic in their formulation. In order to reflect contemporary ethical and legal practice, such policies attempt to marry the public health aims of maximising uptake of testing with a commitment to respect the choices of patients by requiring informed consent before they participate in screening. Thus, in the case of UK policy, health professionals are instructed to recommend the HIV test to all pregnant women in order to achieve the target of a 90% uptake is set,[11] but at the same time those implementing the policy must ensure that

> [i]t is up to each woman to choose whether or not she is tested … and she should not be pressurised into a decision either way. All testing for infections and conditions in pregnancy should be with the woman's knowledge, understanding and consent.[12]

Superficially, this attempt to combine public health goals with respect for the autonomy of pregnant women seems the most ethically acceptable route available to policy makers. However, while both aims are laudable, this paper argues that they are often incompatible and that combining them in this way not only puts those implementing the policy in an impossible situation, but also effectively masks an ethically problematical policy.

## IS INFORMED CONSENT INCOMPATIBLE WITH A HIGH UPTAKE OF SCREENING?

With patient autonomy a central ethical and legal principle in modern medicine, it is generally accepted that competent individuals should be allowed to choose whether or not to have diagnostic tests, especially ones that may indicate potentially serious conditions. Thus, it is normally assumed that the decision to undergo diagnostic tests, particularly those for diseases with serious consequences, should be a fully informed, freely chosen, carefully considered one. The General Medical Council stresses the importance of informed consent for any diagnostic test, emphasising that

> [s]ome conditions, such as HIV, have serious social and financial, as well as medical, implications. In such cases you must make sure that the patient is given appropriate information about the implications of the test, and appropriate time to consider and discuss them.[13]

But while it is usually assumed that HIV testing should, in most circumstances, be freely chosen and preceded by explicit informed consent, antenatal HIV programmes often involve a significantly different approach to consent. Programmes such as the one operated in the UK involve the routine offering and recommendation of an HIV test to all pregnant women, giving them the option of declining the offer.[11] I will argue that there are compelling reasons to suggest that the very nature of this kind of routine testing programme makes gaining valid consent hugely problematic.

First, research has shown that where testing is offered on an ''opt-out'' rather than an ''opt-in'' basis, the uptake will be much greater.[14] One UK study compared an opt-in approach to antenatal HIV testing (in which women had to make an active choice to be tested) with an opt-out approach. It found that the uptake of opt-out testing (88%) was more than double that of opt-in testing (35%). It is argued that even if some of the increase in uptake is due to increased knowledge and changing attitudes (the opt-in study was undertaken in 1996–7 and the opt-out study in 1998), the magnitude of the increase suggests that the approach to testing is important.[15]

Thus, as the fundamental aim of routine testing is to secure the testing of not only those women who would have elected to be tested, but also those women who would not have specifically chosen to be tested, it seems inevitable that pressure will be put on women to accept the test. Furthermore, the fact that a test is made ''routine'' implicitly sends the message that acceptance is recommended.[16] Midwives may even feel it is their duty to persuade women to accept the test, particularly when they are instructed to aim for a 90% uptake. Given this innate characteristic of routine testing, it is unsurprising that the study by Zulueta and Boulton revealed a significant degree of pressure on women to accept testing.[1]

Second, for consent to be valid, the individual must have adequate, accurate information. General Medical Council guidelines on consent to screening, for instance, emphasise that the standard level of information required for informed consent for other medical procedures should be given when testing as part of a screening programme, including a discussion of the uncertainties and risks attached to the programme.[17] Given the time constraints and the need to attain a high uptake of screening, it will usually be impossible for health professionals providing antenatal care to give full and detailed information to all pregnant

women about HIV and measures that can be taken to prevent vertical transmission. If the possible adverse consequences of testing and treatment were emphasised in pre-test counselling, as they would be before HIV testing outside of antenatal care, this would seem likely to result in a lower uptake of testing than if only the positive consequences were emphasised. As an example of the information provided for pregnant women about this matter, it is interesting to note the emotively titled Department of Health leaflet *Better for your baby: HIV testing as part of your antenatal ca*re.[18] This leaflet is intended to be distributed to all pregnant women in Greater London and, as its title implies, strongly recommends the HIV test to pregnant women, offering a very one-sided view of the positive consequences of HIV testing.

The implementation of any routine testing policy which aims for a high uptake cannot by its nature be non-directive and thus will not be compatible with authentic informed consent. Women in many cases will be directed towards being tested and accepting treatments and procedures they would not have chosen if the HIV test were offered in a non-directive way.

However, even if it is accepted that antenatal HIV screening programmes involve a degree of coercion that would be deemed unacceptable in other circumstances, this does not necessarily mean that such testing is ethically unacceptable. There are moral and legal precedents to support directive and coercive practices where these are deemed justified. For instance, health professionals routinely recommend (often in the strongest terms) that their patients stop smoking, cut down their alcohol intake, eat more healthily and take exercise. Similarly, where lack of compliance brings a risk of serious harm to third parties, even the most liberal of commentators accept that a level of coercion may be acceptable to prevent this further harm. This, of course, is the rationale behind traditional public health measures which provide for, in extreme circumstances, the detention or enforced treatment of those with dangerous infectious diseases, in order to protect the wider public from infection. In the United Kingdom, for instance, the Public Health (Control of Disease) Act 1984 empowers public health officers to act to prevent the spread of disease. The powers conferred by that Act and the Public Health (Infectious Diseases) Regulations 1988 permit the state to override virtually all individual liberties in the cause of protecting the community. Similarly, it might be argued that some coercion is acceptable in screening programmes aimed at increasing the uptake of HIV testing in an attempt to protect future children from HIV infection. However, for this argument to be successful, it must be established that the evidence for the imposition of a policy of routine antenatal HIV testing is strong enough to warrant pregnant women being made a special case in which the usual gold standard of informed consent does not apply.

## EVALUATING THE EVIDENCE FOR PREGNANT WOMEN AS A SPECIAL CASE

In the year when routine antenatal HIV testing was introduced in the UK, it was estimated that 380 babies were born in the UK to HIV-positive mothers.[19] Before routine testing was introduced, it was thought that around three-quarters of HIV-positive women did not know at the time of their delivery that they were HIV positive.[20] With the numbers of those infected with HIV steadily rising and with the greatest rise in the UK in the heterosexual population,[21] the number of children being born to HIV-positive women was inevitably set to rise. Clearly, if 90% of pregnant women rather than around 25% were aware of their HIV status, risk-reducing interventions such as the use of zidovudine, birth by caesarean section and not breastfeeding could be offered to many more women, with the result that some children might be spared infection.

For example, in 2000 it was estimated that around 450 HIV-positive women gave birth.[22] On the evidence collected, it seems that where only an opt-in antenatal HIV testing policy exists, we can expect only around a quarter of these 450 women to be aware of their infection.[20] If we accept that the transmission rate is around 2% where these treatments and procedures are adhered to and around 20% where they are not, then if the 25% of these 450 women who are aware of their HIV status are tested and accept treatment but 75% do not, it can be predicted that 70 of the children born to these 450 women will be infected with the virus. If, however, 90% of the 450 women are tested and accept the risk-reducing interventions, it can be predicted that about 17 of the children born to these 450 women will become infected with HIV. Thus, if the UK government's programme of antenatal HIV screening succeeds in reaching its goal of a 90% uptake, and if all the HIV-positive women thus detected accept the treatments offered, about 53 fewer children per year would become infected with HIV in the UK than without the introduction of routine testing.

A result of this magnitude in terms of infection prevention would seem to provide strong justification for routine antenatal screening programmes even if they involve a level of coercion that in other areas of healthcare would be deemed ethically unacceptable. But is this enough to make pregnant women a special case?

The primary goal of routine testing of pregnant women for HIV is to provide them with information that will help prevent them from transmitting this infection to others (their future children). Allowing more infected women access to antiretroviral treatment is also a clear secondary goal.[18] However, the introduction of routine testing of other groups in society would also be likely to further these goals. Routine HIV testing of patients attending genito-urinary medicine clinics, of people exhibiting high-risk behaviour (intravenous drug users receiving treatment for their drug use, perhaps), of all preoperative surgical patients or perhaps simply of all people accessing and providing healthcare services would also be likely to provide individuals with information that would help them minimise HIV transmission to third parties (such as sexual partners, needle sharers, future children, healthcare professionals and patients) and would increase the uptake of antiretroviral therapy. So far, however, calls for more widespread routine HIV testing[8] have been resisted. Why do we resist in these other cases? The reason is that respect for individual autonomy is considered fundamental, even if it results in missed opportunities regarding public health.

## CONCLUSIONS

Antenatal HIV screening programmes have been implemented for extremely good reasons but have tried to marry two commendable but often incompatible aims. If, as I have argued, it may be impossible to produce a high uptake of HIV screening while enabling truly informed choices, then a decision has to be made. Should we allow a degree of coercion or pressuring of pregnant women in order to procure a high uptake of HIV testing, or should we protect informed consent from any erosion? Whatever we choose to do, the choice needs to be transparent and explicit and the reasons behind it stated and debated. At present we are left with a well-intentioned fudge in which a smokescreen that looks like, but is not truly, informed consent conceals levels of coercion that are not deemed acceptable in many other areas of medical testing or treatment. If a compelling case can be made that this coercion is justifiable

given the available evidence, even though it may go against the usual insistence on respect for individual autonomy, then there should be no reason to disguise this. This justification and aim of screening should be made clear.

In attempting to produce such a compelling case, all the aspects of this issue need to be considered extremely carefully. Difficult questions would need to be addressed. Can this infringement of pregnant women's autonomy be prevented from leading to more invasive infringements, such as enforced treatment and caesarean section, on the same grounds? If similar grounds can be used to justify routine HIV screening of other groups in society, then why should we restrict such testing to pregnant women? If we allow infringements of autonomy in the best interests of the patient and to attempt to protect third parties in this case, what will prevent further infringements of autonomy in other areas of medicine, leading back to the outmoded attitude that doctor or politician knows best? In short, a decision needs to be made, not simply with regard to what we do about HIV in pregnancy, but also with regard to the relative importance we should attribute to public health goals and respect for individual autonomy in medicine generally.

And before we contemplate a slide away from respect for patient autonomy, we should consider whether public health goals are really likely to be furthered more by eroding rather than upholding autonomy. Routine antenatal HIV testing programmes aiming for a high uptake of testing and treatment and thus often coercive in nature may not produce the level of benefit predicted. Not all HIV-positive pregnant women will be identified, not all women will adhere to the treatments, there may be some complications arising from the drug regimes and the relationship between midwife and woman may suffer a loss of trust.

Before resorting to coercive screening programmes, it is important that we consider carefully the efficacy of the alternatives. For instance, we could consider implementing an antenatal HIV policy which routinely provided balanced information to all pregnant women in order to accurately inform them of the treatments available for themselves and their children. Any HIV test as a result of this routine HIV counselling would be on the same fully informed voluntary basis as HIV testing in other medical settings. While such a policy might result in a lower uptake of testing, it could, by upholding women's autonomy and providing accurate, balanced information, not only encourage women to be tested for HIV but also make it more likely that they accept the treatments offered. Providing information about HIV in this non-coercive atmosphere might also allow women access to counselling about high-risk behaviours and could therefore help prevent vertical transmission by reducing the numbers of women who become infected with HIV in the first place.

*J Med Ethics* 2007;**33**:446–448.
doi: 10.1136/ jme.2006.018861

Correspondence to: Dr Rebecca Bennett, Senior Lecturer in Bioethics, The Centre for Social Ethics and Policy, School of Law, University of Manchester, Manchester, M16 8DX, United Kingdom; Rebecca.Bennett@manchester.ac.uk

Received 20 October 2006
Accepted 27 October 2006

Competing interests: None declared.

[i]This paper is an updated, revised version of a previous paper: Bennett R. Routine antenatal HIV testing and its implications for informed consent. In: Frith L, Draper H, eds. *Midwifery and ethics*. 2nd edn. Oxford, Butterworth Heinemann, 2004: 74–90.

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